

COMMON REASONS TO SEEK GENETIC SERVICES

- ❧ Medical problems of the developing baby detected by prenatal screening or testing.
- ❧ Harmful exposures during pregnancy such as alcohol or prescription or recreational drugs.
- ❧ Birth defects such as heart problems, structural brain abnormalities, and physical differences like cleft lip and palate.
- ❧ Mental retardation or developmental delays where the person does not reach developmental milestones on time or they do not function developmentally, intellectually, socially or behaviorally as expected for their age.
- ❧ Changes in body chemistry such as extremely high and low protein, fat or sugar levels in the blood.
- ❧ Sensory impairments like vision or hearing problems.
- ❧ Family history of a hereditary disease or cancer.

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HAWAII DEPARTMENT OF HEALTH GENETICS PROGRAM

The **Department of Health Genetics Program** is within the **Children with Special Health Needs Branch**.

The Program aims to:

- ❧ Provide information and education about topics in genetics.
- ❧ Obtain and administer funding related to genetics.
- ❧ Coordinate and support genetics related programs and activities.
- ❧ Support clinical genetic services.
- ❧ Research clinical and public health genetics topics.
- ❧ Develop public policy surrounding genetics.
- ❧ Provide technical assistance to other programs.



The **Genetics Program** also administers and participates in local, regional, and national projects. Some projects that may be of interest to families and providers are:

Western States Genetic Services Collaborative

This is a HRSA funded multi-state project that seeks to improve access to genetic services and education. One of the project's major activities in Hawaii is to increase statewide clinical genetic services by offering neighbor island clinics and telehealth visits.

Sickle Cell Disease Project

This HRSA funded project seeks to develop policies and activities to ensure that newborns and families with Sickle Cell Disease or Trait receive comprehensive care and education.

Tandem Mass Spectrometry Project

This was a HRSA multi-state collaborative project, led by the Hawai'i Department of Health, to obtain research data, identify strategies and develop materials for addressing the financial, ethical, legal and social issues (FELSI) surrounding the use of MS/MS for neonatal metabolic screening of culturally and ethnically diverse populations.

Etiology of Hearing Loss

This was a CDC multi-state collaborative project to determine the cause of congenital hearing loss in children identified through the statewide Newborn Hearing Screening (NBHS) program by offering a genetic evaluation to children with hearing loss.



OTHER RELATED PROGRAMS

Newborn Metabolic Screening (NBMS)

The NBMS Program ensures that newborns in the state of Hawaii receive screening for certain genetic/metabolic disorders. If found and treated before symptoms appear, babies born with these disorders may lead a normal, healthy life.

Newborn Hearing Screening (NBHS)

The NBHS Program ensures that newborns in the state of Hawaii receive screening for hearing loss. If intervention services begin before six months of age, babies with hearing loss have a better chance of learning to communicate as well as babies without hearing loss.

Hawaii Birth Defects (HBD)

The HBD Program collects statewide birth defects information. The information is used to monitor the incidence of birth defects to find any trends or changes over time in our state. The data is also used to develop public health activities to prevent birth defects.

Children with Special Health Needs (CSHN)

The CSHN Program provides medical services, care coordination and support services for children who have or may have long-term or chronic health conditions that require specialized medical care, and their families.